

What Does It Take to Love a Child?



Six years ago, Shirley Lewis Burr picked up a little blue pamphlet that changed her son Jason's life.

Jason was, unofficially, diagnosed as autistic when he was three-and-a-half. He also has epilepsy, an auditory processing disorder and multiple allergies.

At age 10, he was still struggling when Lewis found the brochure that introduced her to "Parents Encouraging Parents" (PEP), a statewide parent-to-parent network established in the Tennessee Department of Health to offer support and information to parents of children with a disability, chronic illness or special need.

The program matches "resource parents" (trained volunteers who have developed effective coping skills in parenting a child with special needs) with "referred parents" (parents with a child who is newly diagnosed, in crisis or transition or simply in need of support and information). Parents are matched as closely as possible based on the child's diagnosis, family structure and cultural, racial or religious factors.

When Lewis Burr found out about the program, she wanted to volunteer to be a resource parent, but felt she needed help, too.

"I thought I knew enough that I could help other parents, but I also knew that I had a long way to go," she said. "I still needed help myself."

PEP matched her with a grandmother of twins with similar diagnoses who had more experience than Lewis Burr.

Parents of special needs children often find it frustrating, expensive and time-consuming to get information about services that their children need. PEP can do a lot of the legwork for them. The program has an extensive print and video lending library, as well as comprehensive databases of local, statewide and national resources.

"I needed a lifetime membership at Kinko's, and I kept both the post office and AT&T in business in my search for information on how to help my son," she said. "And here I found it all in one small office."

PEP provides emotional support and encouragement, as well as practical advice and information to its consumers. Among the information are lists of professionals and providers who can help the parents with a diagnosis or prognosis of their child's situation.



"PEP showed me how to form a circle of cooperation. It was amazing how the circle started coming together. The more I learned, the more services I could get for Jason. This helped me make knowledgeable decisions. And, I had a lot more time to spend with him," she said.

Even after the physical problems are addressed, there's a lot more that goes into finding solutions.

"Parents of typical kids always have a neighbor, aunt or preschool teacher to recommend 'tried and true' solutions to

Above: Jason Lewis performs in the Rhea Central Elementary School Marching Band.

the predictable crises of childhood,” said Holly Lu Conant Rees, parent consultant for PEP. “A parent of a child with special needs often has no such body of collective wisdom from which to draw.

“Physicians and other professionals can give diagnoses and prognoses, suggest surgeries and therapies. But when the questions are, ‘What clothes work best for a baby on a ventilator?’ or ‘Will the other kids tease her?’ the parents of children with special needs do not have a newspaper advice column or a Dr. Spock of disabilities available for answers,” Rees said.

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- Shirley Lewis Burr

Many parents who call PEP have just stepped out of a doctor’s office and are trying to deal with the intense and powerful emotions that accompany the knowledge that their child has special needs. PEP helps them deal with their isolation and confusion.

“When a parent learns his child has a disability or chronic illness, they are suddenly catapulted into a new world with a frightening and unfamiliar landscape,” Rees explained. “That parent is confronted daily with a powerfully disturbing mix of emotions, including fury, guilt and sorrow.”

“It doesn’t fit the typical model of a parent-child bond,” she said. “Many parents are certain, as I was when my son was born, that no other parent in history has experienced, or would admit to, such conflicted feelings about their child.”

Parents Encouraging Parents provides them with a support network so they no longer have to feel alone.

“Parents need someone to talk to and parents with special children don’t know what it’s like because we’re not living in the same world,” Lewis Burr said. “For me, every little accomplishment of Jason’s was cause for celebration, but when I’d talk to my friends, they wouldn’t understand.”

The program which, was started by the Tennessee Department of Health in July 1992, helps parents learn to become advocates for their children.

According to Ben Dishman, Deputy Commissioner of the Department of Mental Health and Developmental Disabilities, the program empowers parents to help children develop to their fullest potential.

“Children with special needs are entitled to develop to their fullest potential in the least restrictive and most nurturing environment available,” Dishman said. “This program empowers parents to help them do just that by giving them reliable information on which to base decisions so they can feel more confident and in control.”

PEP is available to all parents and families that have children with special needs. There are no diagnosis restrictions, and the program is free and available in all 95 counties.

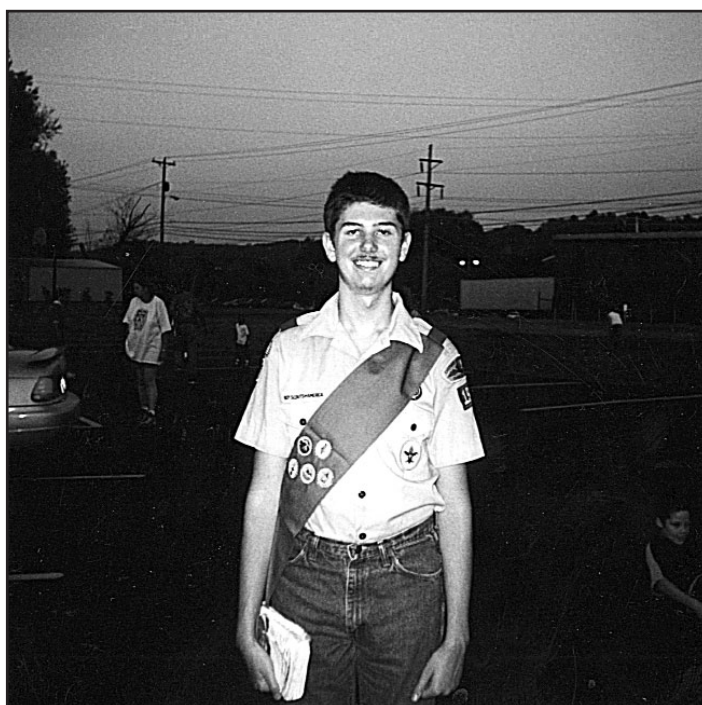
There are currently 232 trained parents in the program. Parents who need assistance or who want to join the network as resource parents should contact their local health department.

The program worked out so well for Lewis Burr that she went to work for PEP as a parent consultant.

“I feel like I’m able to give something back,” she said. “I have the opportunity to share with other parents what I’ve learned so they can utilize some of the same services for the benefit of their children.”

And what about Jason? Four years after PEP entered his life; he was an “A” student in high school and a member of ROTC. He was awarded an outstanding achievement in special education for his progress in school. And, he was able to graduate with a regular diploma.

“He’s opened up so many doors for other kids like him in his community,” his mother said.





Today, Jason is experiencing what it's like being a freshman at Chattanooga State Community College. His course of study is architectural engineering, and he plans on transitioning into a larger school within a few years. With some help by an assistant, a computer keyboard device to take notes and a few other modifications, Jason is being offered an opportunity to succeed. He even lives in his own trailer.

No longer working at PEP, but still an active resource parent, Lewis Burr and her husband are advocates for other mental health issues as well. They plan to use the information they gather to lobby for better programs and facilities throughout the state.



Facing Page: Jason Lewis poses after a Boy Scout meeting. He has been a scout for the past nine years.

Left: Lewis receiving his high school diploma in the spring of 2001.

Above: Parents Encouraging Parents help parents throughout Tennessee. Ms. West Tennessee (center) poses beside Glenda Seilnact and her son, Jason (left), and Donna Guinn and her son, Kyle.

"We want others to know that there are ways to deal with their situations," she said. "Jason would never have got to where he's at today without information and help. He does things that autistics are supposedly not capable of doing.

"Jason has progressed immensely since I found PEP," said Lewis Burr. "He talks, he interacts, he emotes. He walks up to me and says, 'Mom, I love you,' and for an autistic, that's amazing. Jason is doing great because he is surrounded by wonderful professionals, and I found most of them through PEP."

For more information about PEP, contact Suzanne Rothacker, Ph.D., RN at (615) 741-0353.

